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Concordance of Family and Staff Member Reports About End of Life in Assisted Living and Nursing Homes

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Purpose: To identify differences in perspectives that may complicate the process of joint decision making at the end of life, this study determined the agreement of family and staff perspectives about end-of-life experiences in nursing homes and residential care/assisted living communities and whether family and staff roles, involvement in care, and interaction are associated with such agreement. ***Design and Methods:*** This cross-sectional study examined agreement in 336 family–staff pairs of postdeath telephone interviews conducted as part of the Collaborative Studies of Long-Term Care. Eligible deaths occurred in or within 3 days of leaving one of a stratified random sample of 113 long-term care facilities in four states and after the resident had lived in the facility ≥15 days of the last month of life. McNemar *p* values and kappas were determined for each concordance variable, and mixed logistic models were run. ***Results:*** Chance-adjusted family–staff agreement was poor for expectation of death within weeks (66.9% agreement, $\kappa = .33$), course of illness (62.9%, 0.18), symptom burden (59.6%, 0.18), and familiarity with resident's physician (59.2%, 0.05). Staff were more likely than family to expect death (70.2% vs 51.5%, $p < .001$) and less likely to report low symptom burden (39.6% vs 46.6%, $p = .07$). Staff involvement in care related to concordance and perspectives of adult children were more similar to those of staff than were other types of family members. ***Implications:*** Family and staff perspectives about end-of-life experiences may differ substantially; efforts can be made to improve family–staff communication and interaction for joint decision making.

Key Words: Communication, Caregivers, Decision making

In the past few years, there has been an increasing recognition of the ongoing role of family caregivers in nursing homes (NHs) and residential care/assisted living (RC/AL) settings (Gaugler, Zarit, & Pearlin, 2003; Kellett, 2007; Paulus, Raak, & Keijzer, 2005; Port, 2006; Ryan & Scullion, 2000). Family members not only choose to but often believe it is their responsibility to oversee care when their relative moves to these settings (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2006; Kellett; Port et al., 2005). With this involvement comes the need for joint caregiving with facility staff, such that decisions about care are made as a team (Hanson, Henderson, & Menon, 2002). Joint decision making is particularly critical in these

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settings because of the high prevalence of cognitive impairment as more than half of NH and RC/AL residents have dementia or are otherwise unable to participate in decision making (Krauss & Altman, 1998; Sloane, Zimmerman, & Ory, 2001).

Care decisions, such as whether to hospitalize the resident or use artificial nutrition, become more frequent and complex as the end of life nears (Dosa, 2005; Hospice and Palliative Nurses Association, 2004). Because NHs and RC/AL settings are common locations of death (Brock & Foley, 1998; Center for Gerontology and Health Care Research, 2004; Sloane, Zimmerman, Hanson, Mitchell, & Reidel-Leo, 2003), residents, family, and staff in these facilities are regularly faced with the need to make joint decisions about end-of-life issues (Hanson et al., 2002; Munn & Zimmerman, 2006; Wowchuk, McClement, & Bond, 2007). Furthermore, family often takes on a more central role in decision making during this period due to the increased prevalence of cognitive impairment at the end of life when 75% or more of residents are impaired (Mitchell, Teno, Intrator, Feng, & Mor, 2007; Munn et al., 2007; Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006; Wilson, Beckett, Bienias, Evans, & Bennett, 2003). Although there is an extensive body of research examining the role of family members as surrogate decision makers at the end of life and their concordance with patient decisions (Meeker & Jezewski, 2005; Shalowitz, Garrett-Mayer, & Wendler, 2006), little is known about the role of staff caregivers in these decisions and their concordance with residents and families in regard to medical decision making.

Joint decision making between family and staff at the end of life will reflect the extent to which they have similar perspectives on key issues (Murray, Miller, Fiset, O'Connor, & Jacobsen, 2004). One such issue is whether or not the death is imminent as this expectation drives related decisions. There is cause to question agreement on this point because in one study, only one half of resident deaths were expected by family or staff at least a week before the event (Reynolds, Henderson, Schulman, & Hanson, 2002). Thus, a mutual "open awareness" of death in which all parties are aware of and openly acknowledge the impending death (Glaser & Strauss, 1965) is important yet unlikely in this setting. A second important consideration in joint decision making relates to the health status of the dying resident and the extent to which staff and family consider the resident to be uncomfortable and declining (Ferrell, Eberts, McCaffery, & Grant, 1991); agreement on concepts such as symptom burden and the course of illness will drive health care decisions. Finally, end-of-life care involves working with health care providers including physicians (Stewart, Teno, Patrick, & Lynn, 1999). In long-term care settings, physicians have been charged as being "missing in action" (Katz & Karuza, 2005), and so, an indicator as simple as whether or not family or staff are even familiar with the physician has implications for joint care decisions.

By comparing family and staff beliefs about a resident's end-of-life course, as well as their familiarity with the decedent's physician, we can identify similarities and differences of perspectives that may result in difficult decision making. Then, because the relationship between family and staff caregivers is key in the experience of surrogate decision making (Murray et al., 2004; Popejoy, 2005; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007), examining the association between similar beliefs and the family and staff caregivers' roles, involvement in care, and family–staff interaction can illuminate areas of intervention to improve joint decision making. Thus, the aims of this study were to describe the agreement of family and staff member after-death perspectives about end of life and to determine whether family and staff roles, their involvement in care, and family–staff interaction were associated with agreement in family and staff perspectives.

Design and Methods

Study Population

Data for these analyses were collected as part of the Collaborative Studies of Long-Term Care End of Life in Residential Care/Assisted Living and Nursing Homes study. It included a four-state (Florida, Maryland, New Jersey, and North Carolina) stratified random sample of 31 NHs and 199 RC/AL communities (i.e., those that provide room, at least two meals a day, supportive care including medication management, and 24-hr oversight for unscheduled needs). Details about this cohort are available in Zimmerman, Sloane, and Eckert (2001). Facilities were contacted monthly between July 2002 and January 2005 to identify eligible deaths. Deaths were eligible if the resident lived in the facility for ≥15 days of the last month of life and the death occurred in the facility or within 3 days of leaving the facility. For each eligible

decedent, a facility liaison identified the primary staff and family caregivers. The staff respondent was the facility employee who knew the resident the best and provided services such as direct care, supervising direct care, or communicating with family members during the last month of life. Staff members could be interviewed about more than one decedent. The family respondent was the family member, legal guardian, or friend most involved in care decisions during the last month of life. A legal guardian who had no personal relationship with the resident or a staff member was not an eligible family respondent.

Paired staff and family interviews about the same decedent formed the study sample. Of the 1,020 eligible deaths, 168 decedents lacked an eligible family and/or staff respondent. Other deaths were excluded if a family and/or staff caregiver refused to participate (n = 268), if the family or staff caregiver was not reached within 6 months after the death (n = 248), or if data about concordance were missing (n = 4). Thus, the sample for this analysis consisted of 332 family–staff respondent pairs with information about deaths from 27 NHs and 86 RC/AL communities.

Data Collection

Data were collected by telephone interview after consent was obtained. Interviewers waited at least 6 weeks after the death to call family members, whereas staff respondents were contacted by telephone as soon as the death was determined eligible. Forty percent of family interviews and 63% of staff interviews were completed within 3 months postdeath. This study was approved by the University of North Carolina Institutional Review Board (IRB), and the analyses (performed on a deidentified data set) were determined to be exempt from review by the University of Maryland, Baltimore IRB.

Measures

Concordance variables, chosen a priori based on their importance to end-of-life care decisions, included: expectation of death, symptom severity, course of illness, and familiarity with the decedent's physician. Variables were dichotomized for ease of analysis. Expectation of death was determined by asking, "Did you know that [RESIDENT]'s death was imminent? In other words, did you know that [HIS/HER] death was days or weeks away?" Symptom severity was based on a summary index that included questions about pain, shortness of breath, cleanliness problems, and nutrition and hydration (Hanson et al., 2008). Low symptom severity was defined as below the median of 18 (range 0–36). Course of illness in the months leading up to death was categorized by respondents as a slow steady decline, stable health, or a series of ups and downs in health. This variable was dichotomized as slow steady decline versus other responses. Familiarity with the decedent's physician was determined by asking, "What is the name of the physician who was responsible for the care of [RESIDENT] during the last month of life?" and dichotomizing by whether the respondent definitely knew the physician's name. As this variable is likely to indicate involvement in medical decision making and coordination of care, it was examined as both a concordance variable and a potential correlate of the other concordance variables (along with other indicators of involvement in care).

Potential correlate variables were chosen to represent the respondent's role, involvement in care, and family–staff interaction. In addition, the association between familiarity with the physician and the other concordance variables was examined. The family respondent's role was characterized by the relationship to the decedent (adult child, spouse, other relative, or nonrelative). The staff respondent's role was characterized by position (registered/licensed practical nurse [RN/LPN], aide, administrator, or other); the analyses present RNs and LPNs combined because results for these respondents were similar. Family member involvement during the last month of life was determined by a self-reported Likert rating, whereas staff involvement was rated by frequency of involvement in the direct care of the decedent during the last month of life (as per whether the staff member worked with the resident 1–19 days [less than full-time employment], 20–23 days [full-time employment], or 24–31 days [more than full-time employment]) and by length of care (in months). Family–staff interaction was determined by family respondent's report of frequency of speaking with facility staff about the decedent during the last month of life (in days) without regard to the length of these interactions and by a summary measure of the amount of emotional support provided to the family by staff on an 11-item measure (range 0–33) based on Likert ratings of the frequency of support (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001).

An example of its items is "How often did staff members (not including physicians) reassure you that your family member's behavior was not unusual?" Item scores ranged from 0 (never or almost never or no instance) to 3 (always or almost always). These scores were then summed, so that a higher score indicated more support.

Data Analysis

Family–staff agreement within respondent pairs was assessed by frequencies, McNemar *p* values, and Cohen's kappa values from cross-tabulations of all dichotomized concordance variables; by the frequency of agreement and kappa for the three-level course of illness variable; and an intraclass correlation coefficient from a paired *t* test for symptom burden.

To evaluate the relationship between each dichotomized measure of agreement and each potential correlate, generalized linear mixed models were used. These were logistic regressions with the agreement measure as the dependent variable and potential correlates as the independent variables specified as fixed effects; facility was specified as a random effect to account for the hierarchical nature of the data with residents clustered within facilities.

Results

Characteristics of the Study Population

As shown in Table 1, decedents averaged 86.7 years (*SD* 8.9). They were overwhelmingly White and non-Hispanic (91.9%), most decedents were female (71.4%), and most received hospice care (60.1%). Length of stay averaged about 2.5 years (29.0 months), with a wide distribution (*SD* 33.0). Only one decedent had a length of stay less than 1 month. Family respondents were similar to decedents in race–ethnicity and sex. They averaged 60.6 years (*SD* 11.6); most were adult children of decedents (66.6%) and most reported very high involvement in care (54.8%). The mean age of staff respondents was 44.0 years (*SD* 11.4). Most were White and non-Hispanic (56.9%), although a substantial percentage was African American (29.7%). Staff respondents were most often nurses (52.1%), with RNs making up 20.9%; a notable percentage were aides (29.3%). Staff reported caring for the decedent on about a full-time schedule in the last month of life (*M* 20.3 days, *SD* 5.6).

Distribution of Family–Staff Agreement

Death was significantly more likely to be expected by staff than by family respondents (70.2% vs 51.5%, respectively; $p < .001$; Table 2). Agreement was moderate (κ .33), with 44.3% of respondent pairs agreeing that death was expected and 22.6% of pairs agreeing that death was not expected.

Family respondents were somewhat more likely to report a low symptom burden than staff members (46.6% vs 39.6%, respectively; $p = .07$), and agreement was low (κ .18). When treated as a continuous variable (data not tabulated), symptom burden ratings were similar for staff and family respondents (*M* 18.1 [*SD* 6.9] vs 17.5 [*SD* 7.0], respectively; $p = .23$). The intraclass correlation coefficient was .27.

Similar percentages of staff and family respondents described the course of illness as slow steady decline (64.3% vs 66.8%, respectively; $p = .47$ for this dichotomized variable). There also was no evidence of a difference in the marginal distributions for family and staff respondents examining all three trajectory responses ($p = .70$; data not shown). Agreement was low for both the dichotomized variable (62.9%, κ .18) and the original three-level variable (57.3%, κ .15).

Finally, a similar percentage of staff and family respondents were familiar with the decedents' physicians (69.9% vs 67.8%, respectively; $p = .54$), but agreement was very low (κ .05). About 11% of decedents had physicians who were unfamiliar to both the staff and the family.

Potential Correlates of Family–Staff Agreement

Few potential correlates showed an association with the concordance variables (Table 3). There was a significant trend ($p = .04$) between greater staff involvement in care and concordance in familiarity with the resident's physician when the continuous data for frequency of staff involvement in last month of life were treated as a three-level variable. Marginal associations ($p < .10$) were found between family relationship and concordance in symptom burden and familiarity with physician. Concordance in symptom burden was marginally less likely for pairs with spouses and significantly less likely for those with other relatives compared with those with adult children (i.e., 46% among pairs with spouses vs 65% with adult children and 50% with other relatives). Concordance in physician familiarity was marginally more likely for pairs with nonrelatives

Table 1. Study Sample Distribution of Decedent Characteristics, Family and Staff Respondents' Characteristics, and Staff Involvement

	N (%)	*M* (*SD*)
Decedent characteristics (*n* = 332)		
Age (years)		86.7 (8.9)
Race–ethnicity		
White, non-Hispanic	305 (91.9)	
White, Hispanic	7 (2.1)	
African American	17 (5.1)	
Other	3 (0.9)	
Female	237 (71.4)	
Received hospice care	184 (60.1)	
Facility type[a]		
Nursing home	157 (47.3)	
RC/AL <16 beds	56 (16.9)	
Traditional RC/AL	28 (8.4)	
New-model RC/AL	91 (27.4)	
Length of stay (months)		29.0 (33.0)
Family respondent characteristics (*n* = 332)[b]		
Age (years)		60.6 (11.6)
Race–ethnicity		
White, non-Hispanic	305 (92.1)	
White, Hispanic	7 (2.1)	
African American	17 (5.1)	
Other	2 (0.6)	
Unknown	1 (0.3)	
Female	239 (72.0)	
Relationship		
Adult child	221 (66.6)	
Spouse	25 (7.5)	
Other relative	64 (19.3)	
Nonrelative	22 (6.6)	
Level of involvement		
Very low, low, and moderate	65 (20.1)	
High	81 (25.1)	
Very high	177 (54.8)	
Days spoke with staff in last month		15.5 (10.4)
Emotional support from staff[c]		23.6 (8.7)
Staff respondent characteristics (*n* = 215)[d]		
Age (years)		44.0 (11.4)
Race–ethnicity		
White, non-Hispanic	119 (56.9)	
White, Hispanic	6 (2.9)	
African American	62 (29.7)	
Other	22 (10.5)	
Female	201 (93.5)	
Position		
RN/LPN	112 (52.1)	
Aide	63 (29.3)	
Administrator	24 (11.2)	
Other	16 (7.4)	

(Table continues on next page)

Table 1 *(continued)*

	N (%)	*M* (*SD*)
Staff involvement (n = 332)[e]		
Days staff respondent was involved in direct care of resident in last month		20.3 (5.6)
How long staff respondent cared for resident (months)		21.6 (22.8)

Notes: RC/AL = residential care/assisted living community; RN/LPN = registered nurse/licensed practical nurse.

[a]Traditional RC/AL communities are similar to board and care, whereas new-model RC/AL communities tend to provide nursing care and serve a more impaired population. (See Zimmerman et al., 2001, for more details.)

[b]Family respondent race–ethnicity was missing for one respondent; family respondent age and reported level of involvement were missing for nine respondents.

[c]Summary measure of the degree of emotional support provided to the family by staff on an 11-item measure (range 0–33; Whitlatch et al., 2001). This measure was based on Likert ratings of the frequency with which staff provided support, including reassuring the family member that the resident's behavior was not unusual, helping the family member to know who to contact at the facility regarding a problem, encouraging the family member to talk about fears and concerns, keeping the family member informed about changes in the resident's condition, understanding that having the resident there was stressful for the family member, answering the family member's questions promptly, answering the family member's questions clearly, listening to the family member's concerns, providing support in dealing with the family member's feelings about the death, talking with the family member about how he or she might feel after the resident's death, and suggesting someone the family member could turn to for help if he or she was feeling stressed.

[d]Staff respondent characteristics are reported for the 215 unique staff respondents who reported on residents in this study. Race–ethnicity and age were missing for six staff respondents.

[e]Involvement with particular residents as reported by staff are provided for the 332 residents in the sample. Duration of resident care was missing for six residents and days involved in direct care in last month were missing for one resident.

compared with those with adult children (i.e., 82% among pairs with nonrelatives vs 60% with adult children).

For family–staff pairs reporting on decedents who received hospice care compared with those who did not (data not tabulated), agreement on course of illness was significantly greater (62% vs 49%; p = .03) and agreement on symptom burden was marginally less (56% vs 67%; p = .09). There was no statistically significant difference in agreement on expectation of death or familiarity with physician based on decedent's hospice use (results not shown). There were no statistically significant differences in agreement based on facility type (NHs vs RC/AL communities).

Discussion

To our knowledge, this is the first study to examine the agreement between family and staff members' perspectives about a long-term care resident's death. Given the important role of family caregivers in long-term care settings (Kellett, 2007; Ryan & Scullion, 2000), decisions for care at the end of life are often a joint effort between family and staff members (Hanson et al., 2002; Murray et al., 2004; Wowchuk et al., 2007). Joint decision making is easier if perspectives are similar regarding the resident's status, particularly on such central issues as whether death is expected and the extent to which the individual is suffering.

Although the majority of family and staff respondents agreed on each of the variables examined, we

Table 2. Agreement of Family and Staff Respondents for Expectation of Death, Symptom Burden, Course of Illness, and Familiarity with Physician (N = 332 pairs)[a]

Characteristic	Overall, *N* (%) Yes		McNemar	Agreement, *N* (%)		
	Staff	Family	p value[b]	Both yes	Both no	κ
Death expected	233 (70.2)	171 (51.5)	<.001	147 (44.3)	75 (22.6)	.33
Low symptom burden	109 (39.6)	128 (46.6)	.07	63 (22.9)	101 (36.7)	.18
Course of illness slow steady decline	211 (64.3)	219 (66.8)	.47	154 (47.0)	52 (15.9)	.18
Familiar with physician	228 (69.9)	221 (67.8)	.54	158 (48.5)	35 (10.7)	.05

[a]*Notes*: Due to missing data, there are 275 pairs for symptom burden, 328 pairs for course of illness, and 326 pairs for familiarity with physician.

[b]Tests for a difference in the proportions for paired data.

Table 3. Association of Selected Family and Staff Characteristics With Agreement of Family and Staff Respondents for Expectation of Death, Symptom Burden, Course of Illness, and Familiarity with Physician[a]

		Concordance							
		Expectation of death		Symptom burden (high or low)		Course of illness (three levels)		Familiarity with physician	
	N	*n* (%)	*p*	*n* (%)	*p*	*n* (%)	*p*	*n* (%)	*p*
Family relationship									
Adult child	221	148 (67.0)	ref	118 (64.8)	ref	121 (55.8)	ref	131 (60.1)	ref
Spouse	25	13 (52.0)	.17	10 (45.5)	.08	15 (60.0)	.69	11 (45.8)	.23
Other relative	64	45 (70.3)	.63	27 (50.0)	.05	40 (62.5)	.34	33 (53.2)	.39
Nonrelative	22	16 (72.7)	.60	9 (52.9)	.71	12 (54.5)	.91	18 (81.8)	.06
Staff position									
RN/LPN	204	141 (69.1)	ref	104 (62.3)	ref	123 (61.5)	ref	119 (59.2)	ref
Aide	77	47 (61.0)	.16	37 (56.1)	.38	41 (53.2)	.21	40 (54.1)	.41
Administrator	32	18 (56.3)	.13	12 (52.2)	.36	15 (46.9)	.12	22 (68.8)	.36
Other	19	16 (84.2)	.20	11 (57.9)	.71	9 (47.4)	.24	12 (63.2)	.68
Family member involvement									
Low moderate	65	42 (64.6)	.66	26 (53.1)	.20	32 (50.0)	.14	35 (53.8)	.40
High	81	57 (70.4)	.53	42 (58.3)	.46	46 (57.5)	.62	48 (59.3)	.95
Very high	177	117 (66.1)	ref	94 (63.5)	ref	107 (60.8)	ref	104 (60.1)	ref
Staff member involvement in direct care in last month of life									
<Full-time employment (1–19 days)	65	46 (70.8)	.77	28 (54.9)	.59	35 (54.7)	.43	33 (51.6)	.04
Full-time employment (20–23 days)	191	120 (62.8)	.14	99 (60.7)	.92	107 (56.9)	.51	110 (58.2)	.13
>Full-time employment (24–31 days)	75	55 (73.3)	ref	36 (60.0)	ref	46 (61.3)	.35	50 (69.4)	ref
How long staff member cared for resident (months)									
0–5	88	56 (63.6)	.50	46 (62.2)	.48	52 (61.2)	.35	46 (53.5)	.93
6–12	81	51 (63.0)	.55	40 (58.8)	.72	51 (63.0)	.26	55 (67.9)	.12
13–36	106	80 (75.5)	.04	53 (58.9)	.71	55 (52.4)	.95	61 (58.7)	.66
37–120	51	30 (58.8)	ref	21 (55.3)	ref	27 (52.9)	ref	28 (56.0)	ref
How often family member spoke with staff in last month of life									
<Weekly (0–3)	40	28 (70.0)	.58	20 (60.6)	.56	20 (51.3)	.20	23 (57.5)	.79
Weekly or a few times a week (4–14)	128	85 (66.4)	.73	59 (57.8)	.66	68 (53.5)	.16	77 (60.6)	.51
Almost daily (15–29)	84	59 (70.2)	.40	48 (67.6)	.11	49 (59.0)	.55	49 (60.5)	.58
Daily (30–31)	78	50 (64.1)	ref	37 (54.4)	ref	49 (63.6)	ref	43 (56.6)	ref
Emotional support from staff									
Lower 1/3	104	70 (67.3)	.82	54 (64.3)	.47	61 (58.7)	.99	61 (59.8)	.55
Middle 1/3	104	69 (66.3)	.69	52 (60.5)	.84	57 (55.3)	.62	62 (60.2)	.49
Upper 1/3	110	75 (68.2)	ref	56 (58.9)	ref	64 (58.7)	ref	61 (56.0)	ref
Family member definitely knew physician									
No	106	69 (65.1)	.53	51 (59.3)	.94	53 (51.0)	.11	N/A	
Yes	224	153 (68.3)	ref	113 (59.8)	ref	134 (60.4)	ref		
Staff member definitely knew physician									
No	98	65 (66.3)	.90	49 (62.0)	.58	50 (51.5)	.22	N/A	
Yes	230	153 (66.5)	ref	112 (58.3)	ref	134 (59.0)	ref		
Both definitely knew physician									
No	168	108 (64.3)	.36	82 (60.3)	.77	87 (52.4)	.10	N/A	
Yes	158	110 (69.6)	ref	79 (58.5)	ref	96 (61.5)	ref		

Notes: N/A = not applicable; RN/LPN = registered nurse/licensed practical nurse.

[a]Based on logistic mixed models with particular type of agreement as the dependent variable, specifying random effect for facility, family and staff measures as fixed effects. Analyses are unadjusted, that is, each family and staff characteristic or measure of involvement was tested one at a time, in separate models.

found that discordant perspectives were common. Between 30% and 40% of family–staff pairs disagreed about whether the death was expected, whether the symptom burden was low or high, and what type of trajectory the decedent experienced. Agreement according to kappa was fair or poor in

all cases. It is of some concern that discordance was common for these basic beliefs about the resident's death because while there may be no "right" answer for these beliefs, a shared perspective may be an important prerequisite for successful joint decision making. For example, if a family member does not expect death but a staff member does (as in 26% of the pairs, data not shown), the family member may push for more aggressive interventions than the staff member considers appropriate. The alternate situation is less likely, as in only 7% of pairs did the family member expect the death when the staff member did not (data not shown). In fact, as shown in Table 2, staff members expected the death in 70% of the cases compared with 52% for families, indicating that when family members expected the death, the staff member was likely to expect it as well. In a similar way, discordance in perspectives about the resident's degree of symptom burden or trajectory is likely to lead to disagreement about what is considered appropriate care.

As a possible indicator of involvement in care coordination, the poor concordance of familiarity with the decedent's physician introduces a different concern. About 70% of family respondents and staff respondents were each familiar with the physician's name, but only 49% of pairs were both familiar with the physician. This lack of agreement may be due in part to a difference in schedules since families may visit at times when the staff members most involved in providing care are not working (e.g., nights or weekends). Thus, there seems to be an opportunity to increase staff involvement in family–physician communication and family involvement in staff–physician communication. Doing so may also increase the expectation of death, as has been found in other analyses (Biola et al., 2007).

Although many potential correlates of concordance were not significantly associated with concordance in this study, there is indication that the greater staff involvement with residents, the more likely that they and the family will know the resident's physician. This finding is only preliminary, but it is further evidence supporting the importance of stable staffing in long-term care. Among family characteristics, the perspectives of adult children tended to be more similar to staff related to symptom burden than were those of other family relations. Considering that adult children are more often involved in care than other relatives (i.e., they constituted 67% of respondents), the opportunity for concordance is already maximized in this context.

As an initial study in a new area of exploration, this project has some limitations. We relied on postdeath interviews, although this limitation was common to both respondents. We also relied on a relatively limited number of questions to examine family and staff perspectives and possible correlates; we had no staff measure of interaction with family and no specific measure of interaction between the family and staff respondents. We also were limited to examining only a few aspects of family and staff perspectives; future research should examine the concordance on additional factors, particularly expectations and preferences for care. Furthermore, the study sample was predominantly White, reflecting the national distribution of race in these settings; however, these results may not be generalizable to other racial or ethnic groups or to settings with a different racial distribution.

This study found substantial disagreement between family and staff caregivers in their perspectives about the end-of-life circumstances for a resident of a NH or RC/AL community. Further studies are needed to characterize the agreement of family and staff perspectives about end of life. In particular, more study is needed to understand how the differences between family and staff perspectives affect decision making about resident care and whether and how agreement contributes to joint decision making and the resulting quality of care.

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